Building Bridges

Mental Health Consumers and Primary Health Care Representatives in Dialogue



U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES
Substance Abuse and Mental Health Services Administration
Center for Mental Health Services



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Disclaimer

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Foreword

Mental health is essential to overall health, and Americans are becoming increasingly aware of the connection. The United States, however, has traditionally had a "system" of care in which mental health has been set apart, separate from primary or general health care. Now that it is understood that mental and general health are inextricably linked, the two disciplines must be brought together. It is essential to facilitate access for persons with mental health problems to high-quality, affordable, coordinated mental and general health care that is provided in a way that makes sense in their lives.

Many changes must take place to accomplish this integration at the Federal, State, and local levels, as discussed in *Achieving the Promise: Transforming Mental Health Care in America*, the final report of the President's New Freedom Commission on Mental Health (2003a) and *Transforming Mental Health Care in America—The Federal Action Agenda: First Steps* (2005). The Substance Abuse and Mental Health Services Administration (SAMHSA) and its Center for Mental Health Services (CMHS) are working to transform the way that services are provided for people who experience mental health problems nationwide.

The Commission's transformation goals are presented in the box below. Goal 1 highlights Americans' lack of awareness that mental illnesses can be treated and that recovery is possible. The Commission stated the imperative to "address mental health with the same urgency as physical health."

New Freedom Commission on Mental Health: Transformation of the U.S. Mental Health System

- Goal 1. Americans understand that mental health is essential to overall health.
- Goal 2. Mental health care is consumer and family driven.
- Goal 3. Disparities in mental health services are eliminated.
- Goal 4. Early mental health screening, assessment, and referral to services are common practice.
- Goal 5. Excellent mental health care is delivered and research is accelerated.
- Goal 6. Technology is used to access mental health care and information.

Source: New Freedom Commission on Mental Health. (2003). *Achieving the Promise: Transforming Mental Health Care in America. Final Report*. DHHS Pub. No. SMA-03-3832. Rockville, MD. www.mentalhealthcommission.gov

CMHS's traditional focus has been on providing mental health services. But in discussions of integrating primary health care with mental health, prevention of mental illnesses and promotion of mental health must also be considered. The more that mental health promotion, mental illness prevention, and substance abuse prevention become part of the prevention agenda for public health, the better the stage can be set for developing the financing mechanisms and policies that will make transformation possible.

A series of CMHS dialogue meetings has examined approaches that impact personal and, ultimately, systems transformation. Participants in the dialogues share their own relevant experiences that promoted or hindered recovery. Both personal and systems transformation depend on relationships and connections between people, and dialogues help to identify barriers and to forge relationships that lead to recommendations and actions that foster recovery for consumers of mental health services.

In March 2005, CMHS sponsored a dialogue between invited consumers of mental health services and representatives of various sectors of the primary health system. In an effort to develop improved mutual understanding, respect, and partnerships, the two dozen participants

- Identified issues involving mental health consumers and their experiences with primary care providers, including those that both hinder and help recovery; and
- Developed recommendations regarding attitudinal shifts and systems transformation that can lead to improved mental and general health care responses to people with mental illnesses by primary care and mental health providers.

The participants' findings and recommendations are summarized in this publication to be helpful when engaging in activities that promote mental health systems transformation.

Contents

Overview	1
Dialogue Themes and Findings	5
In Their Own Words	5
Issues of Personhood and Relationships	
Person-Level Factors That Promote Recovery	10
Person-Level Factors That Hinder Recovery	11
Issues Related to Systems and Contexts	12
System-Level Factors That Promote Recovery	12
System-Level Factors That Hinder Recovery	15
Recommendations for Action	21
Communication and Engagement of Mental Health and	
Primary Care Providers in Integrating Care	21
Stakeholder Education	23
Stakeholder Accountability	24
Research	25
Finance	26
Planned Actions in the Community	
Selected References and Resources	31
References and Related Publications	
Federal and Other Resources	34
Participant List	41

Overview

Our country must make a commitment: Americans with mental illness deserve our understanding, and they deserve excellent care. They deserve a health system that treats their illness with the same urgency as a physical illness.

—President George W. Bush (2002)

Although mental health and general health are clearly connected, a chasm exists between the mental health care and general health care systems in both practice and financing. The intersection of mental health and primary health, under discussion since the mid-1990s, recently has garnered increased attention and concern at the national and State levels. It has become apparent that consumers of mental health services experience unnecessary suffering, functional impairment, mortality, economic losses, and health care costs as a result of ineffective care due to the fragmentation of the Nation's multiple health care systems. The President's New Freedom Commission on Mental Health found that mental illnesses are shockingly common and affect almost every American family (New Freedom Commission, 2003a).

The effects of the dichotomy in care are evident in both general medical settings and mental health settings. For example, half of the care for common mental disorders is delivered in general medical settings (New Freedom Commission, 2003a), and 35 percent of persons with serious mental disorders have at least one medical disorder that is not diagnosed (Bazelon Center, 2004). The reports of the President's New Freedom Commission on Mental Health (2003a) and its Subcommittee on Mental Health Interface with General Medicine (New Freedom Commission, 2003b) describe the extent and seriousness of the problem:

- Mental health problems are common in primary care.
- Mental health problems commonly occur with other general medical conditions. Studies have shown that adults with common general medical disorders, such as coronary heart disease, have high rates of depression and anxiety. Depression also impairs self-care and adherence to treatments for chronic medical illnesses.
- Mental health problems often go undiagnosed and untreated or undertreated in primary care. Studies show that effective treatments for most common mental disorders are rarely used effectively in primary care. Older adults, children and adolescents, individuals from ethnic minority groups, and

patients uninsured or of low income seen in the public sector are particularly unlikely to receive care for mental health problems.

- Individual, provider, and system factors contribute to poor quality care on the primary care–mental health interface:
 - Persons may fail to recognize or correctly identify their symptoms of mental illness, and even when they do, they may be reluctant to seek care because of stigma and discrimination.
 - Primary care providers may lack the necessary time, training, or resources to provide appropriate treatment for mental health problems.
 - Last, mental health benefits typically are more restricted and more heavily managed than other medical benefits. Lack of parity for insurance coverage between mental health and general medical care represents an ongoing system-level barrier to obtaining needed mental health services in the United States.
- General medical disorders are common, but often they are treated poorly in specialty mental health care settings. The problems underlying the gaps in medical care of individuals with serious mental illnesses parallel the problems that occur in the treatment of depression and anxiety disorders in general medical settings.
- Mental health financing poses challenges. Insurance plans
 that place greater restrictions on treating mental illnesses
 than on other illnesses prevent some individuals from getting
 the care that would dramatically improve their lives. Mental
 health benefits traditionally have been more limited than other
 medical benefits in both private and public health insurance
 programs.

For each of its six goals, the Commission offered recommendations to transform systems that provide—or should provide—support for mental health recovery. In **Recommendation 1.2**, the Commission stated the imperative to "address mental health with the same urgency as physical health." Essentially, general health providers must develop the capacity to recognize and either treat or refer individuals who need more specialized care. Mental health providers must develop the capacity to recognize when consumers of their services need attention for their general medical problems and to refer them for appropriate care.

Recommendation 1.2: Address mental health with the same urgency as physical health.

Recognize the Connection Between Mental Health and Physical Health

Health care and other human service systems should treat adults with serious mental illnesses and children with serious emotional disturbances with the same dignity, urgency, and quality of care that is given to people with any other form of illness. Doing so can contribute greatly to reducing stigma while encouraging people in need to seek help. . . . Good mental health improves the quality of life for people with serious physical illnesses and may contribute to longer life in general. (New Freedom Commission, 2003a)

In **Recommendation 4.4**, the Commission called for screening "for mental disorders in primary health care, across the lifespan, and connecting to treatment and supports."

Recommendation 4.4: Screen for mental disorders in primary health care, across the lifespan, and connect to treatment and supports.

Expand Screening and Collaborative Care in Primary Care Settings

Collaborative care models should be widely implemented in primary health care settings and reimbursed by public and private insurers. Numerous studies have documented the effectiveness of collaborative care models. Expanded screening and collaborative care . . . could save lives. . . .

The federal government could better coordinate the funding and the clinical care provided by publicly funded community health clinics to consumers with multiple conditions, including physical, mental, and co-occurring substance abuse disorders. (New Freedom Commission, 2003a)

In recent years, numerous meetings, reports, and papers have addressed the issue of the integration of mental health and primary health care, and a number of ongoing initiatives are working to effect the integration (see "Selected References and Resources"). Despite these initiatives, little face-to-face discussion has taken place between mental health consumers and representatives of the primary care system on what is needed on the interface between primary and mental health care to promote recovery.

In March 2005, hosted by CMHS, a group of mental health consumers met with primary care providers, researchers, and policymakers in dialogue. The meeting provided a forum in which to develop trust and to build mutual understanding and respect, a first step toward creating effective alliances that support recovery for consumers who come into contact with primary care systems. The participants shared the understanding that recovery from mental illnesses is now a possibility—even an expectation. Persons with mental health diagnoses now can expect to achieve satisfying, hopeful, purposeful, and contributing lives—despite any limitations their disorders may cause. The efforts of a burgeoning cadre of consumer advocates and peer supporters across the country have been critically important in fostering hope and the means and methods for consumers to set and achieve their goals for a meaningful life in the community.

Among other topics, dialogue participants discussed

- Access to, and the availability, affordability, and quality of, medical and mental health services;
- Interaction of general health and mental health;
- Role, practice, and purview of primary care in mental health care and of mental health care in primary health care;
- · Cultural and other disparities;
- · Medications and side effects;
- · Financing;
- · Cross-training in primary care and mental health care; and
- · Recovery orientation of care.

The participants discussed their experiences, identified factors that promote and hinder recovery of persons in general and mental health care systems, described instances in which medical conditions were not adequately diagnosed and treated in mental health care settings, as well as instances in which mental health problems were not adequately diagnosed and treated in general health care settings. Participants synthesized their discussions and developed recommendations to address attitudinal and bureaucratic barriers and to create opportunities for promoting recovery.

Dialogue Themes and Findings

"I am a whole person, and all my parts come together."

-Family member, consumer, policymaker

In Their Own Words

Participants introduced themselves and shared relevant personal and professional experiences related to the intersection of mental health and general health.

... My primary care doctor would never ask me about mental health issues, how I was doing on an emotional basis. He would consider physical illnesses only from a biological perspective, and how I was doing and feeling never came up in all those years.

—Consumer, policymaker

... We're talking about two dimensions: to equip and empower primary care physicians to recognize and treat mental health problems, and to ensure that consumers who receive mental health care receive high-quality general medical care.

-Mental health provider, advocate, educator

... Primary care must see mental health as part of its charge and responsibility, and vice versa. The ultimate goal is for primary care and mental health care to work together. Developing a coordinated plan is the context for all work.

-Mental health administrator

At the heart of many of their comments was the toxic effect of stigma and discrimination . . .

. . . I am overweight, Black, and a trauma survivor. I have to do a lot of working with people to get them to notice my physical complaints. I keep trying to get my rights.

-Consumer/advocate

. . . I felt stigma and shame for many years, which kept me from seeking services.

-Consumer, policymaker

... The African American community needs a lot of education on identifying when there's a problem, and then getting help. Often we're told, "Just pray a lot." "Just be strong." It's looked upon as a character flaw if we have any mental problems.

-Advocate

And of many mental health providers' lack of knowledge about current mental health approaches. . . .

I heard about recovery in 1998, but at one point a psychiatrist told me my illness was "like a record. Every year the needle goes around and makes deeper and deeper scratches, until someday there are only scratches —no music." Immediately I changed providers.

-Consumer, service provider

Some participants recounted instances in which general medical conditions were not adequately treated in mental health settings. . . .

... Of a bundred consumers we surveyed about their general health care, twenty-six had diabetes, but only three people had had any diabetes-care education and only one had had a blood test. The group had an aggregate of 130 visits to the emergency room. But with grant funds, we held a wellness education meeting and then hired nurses to work in community mental health centers to incorporate physical wellness into recovery. Preliminary data show a 10 percent cost savings from avoidance of emergency room visits.

—State policymaker

Others described instances in which inappropriate attention to mental health issues in primary care settings was given. . . .

... When I'm depressed, I do have real physical symptoms. I had to be aggressive to get my doctor to follow through on my complaints about severe fatigue that felt different from regular depression. At first he said it was "just depression," but after a series of tests, it turned out I had anemia. Learning that I had anemia made me feel good, since it demonstrated that I wasn't totally crazy.

-Consumer/advocate

... Most people in my State with mental illnesses find getting day-to-day health care very difficult. When they do access it, all physical symptoms filter through our psychiatric diagnoses, and it's sometimes difficult to get physicians to listen to the real issues. Psychiatric symptoms often are physically based, but the problems I experience related to my thyroid have nothing to do with depression.

-Consumer/advocate

Some participants observed that mental health consumers often do not receive the dental care they require. . . .

... Forty percent of consumers had uncared-for dental needs when I became county medical director. After one consumer received dental care, her panic attacks decreased by 95 percent.

-Primary care provider, educator, researcher

Some described how support from other consumers made a difference in their health and their lives. . . .

. . . I became involved a long time ago with the consumer movement, because I found more hope, strength, and courage with consumers than I had anywhere else.

-Consumer/advocate

Others offered their perspectives on the particular vulnerability of persons who are members of minority groups and other special populations. . . .

... Providers often overlook depression as an accompaniment to general medical problems, and when they occur in minority populations, there is even less recognition of how symptoms might present. . . . We need to educate providers about co-occurring disorders.

-Family member, primary care provider, educator

And others asserted that healing relationships with providers make all the difference. . . .

. . . Everything is built on relationships and communication.

-Consumer advocate/peer specialist

... Because of today's rapid-paced health care system, providers have lost the ability to wonder about who is this person, to try to figure out how best to help. Better ways exist to address mental health issues than the way our claims system forces us to.

—Primary care provider, educator, researcher

Some described their perspectives on research. . . .

. . . I am concerned that research on evidence-based practices is not recovery focused.

-Consumer/advocate

. . . Improvement of patient safety in mental health is critical. To improve quality it is important to "follow the deaths." States,

or even law enforcement, can aggregate information across populations for analysis.

-Mental health provider, researcher

In the words of a consumer/advocate...

I don't remember a time before mental illness. My parents were told that I would never succeed in society and to put me in an institution. They didn't, but throughout the years, I have had many misdiagnoses and a lot of medications that didn't help me. Just in the past fifteen years have I been able to reach toward recovery.

I became involved a long time ago with the consumer movement, because I found more hope, strength, and courage with consumers than I have anywhere else. Most of all, it was the acceptance; I didn't have to explain who I was. Talking with professionals is not the same as seeing consumers living lives of joy—and, yes, of troubles.

In the early 1990s, I worked to establish a statewide consumer organization. In that one year, three consumers had died in one state hospital in Virginia. They were young people, all of them with medical conditions, and they died within three months of each other. On the eve of the first statewide consumer conference, we held a memorial service. We allowed time for consumers to call out the names of other consumers—friends—who had died in the past year. Forty-five minutes later, we ended the service. We had heard so very many names. It was so stunning.

I was appointed as the first publicly self-identified consumer to serve on the state board of mental health. I discovered that when people like us die in hospitals, critical incident reports must be completed and a root cause analysis conducted. But those of us in the community just disappear.

I've become aware of how young we are when we consumers die, typically from causes that are eminently preventable. Poverty explains part of the problem, but we are a medically fragile population. We have many autoimmune diseases with inflammatory processes that produce extraordinary fragility. We also can place some blame on a medical care system that we have hard time accessing and on doctors who don't know how to talk to us, don't trust what we say, and don't adequately report our symptoms. When doctors treat us, they need to be more probing and to try to do things differently so that people can live.

In the words of a primary care provider...

I am a pediatrician and a family member of a person with a mental illness. If I had to take just one message to mental health providers, it would be that the family is the patient—not just the patient. I have felt excluded and frustrated. Even though my spouse and I are guardians and caregivers, we have gone months without an opportunity to speak with the psychiatrist....

Pediatricians want to do something about mental health, because we can't take adequate care of our kids. We have no relationship with mental health providers in the community, and we can't get reimbursed.

Nevertheless, we have accomplished some wonderful things in my State. We have been able to secure reimbursement for twenty-six unmanaged mental health visits annually, including six visits without a diagnosis, for a primary care physician. The American Academy of Pediatrics is very interested in our work.

I teach pediatric residents advocacy and I teach behavioral health. In our community, the greatest unmet need is behavioral health services, and as a faculty, we are modeling personal change in response to that need. We are enriching the curriculum and sending residents into agencies that care for families and on home visits to children with chronic illnesses. We also have become involved with schools, which are de facto mental health providers, and we are developing community protocols for exchanging confidential information.

The most recent state mental health plan was created without pediatricians at the table. General pediatricians are small business owners. We need to meet a payroll, and we're accountable for a certain level of productivity. In any hour, should we see six kids with sore throats or just one child with a complex mental health issue? What we do is to see the child with mental health problems last in the day, on our own time, because, under the existing insurance rules, we cannot obtain adequate reimbursement.

As pediatricians, we need screening tools for mental health, and we need to establish relationships with mental health providers. If I have a child with an orthopedic problem, I can make referrals and get feedback. But if I refer a child to a mental health provider, I rarely hear anything back—and if it's a referral to the public mental health sector, it's a black hole. Patients must follow up on referrals on their own; if I call to follow up, I can't get through.

Issues of Personhood and Relationships

Participants identified a series of person-level factors that promote and that hinder recovery. These factors are listed below.

Person-Level Factors That Promote Recovery

Participants identified the overarching value of all stakeholders understanding the concepts of recovery and wellness, including the acknowledgment that recovery is possible; the importance of prevention programs; and the roles that spirituality, joy, and hope can play. Other person-level factors that promote recovery include

- Primary care providers who incorporate wellness into care, work at a continuously healing relationship, and respect persons with psychiatric diagnoses. Respect can take the form of active listening, taking complaints seriously, attention to followup, truthfulness, self-disclosure, creativity in communicating with consumers, time management in delivery of care, acknowledgment of their own limitations, and advocacy on behalf of consumers.
- Primary care and specialty mental health providers who communicate with each other to coordinate care on general medical and psychiatric issues.
- Providers who encourage active consumer (and family) involvement and dialogue in decisionmaking on care.

 We need to focus more on	methods of engagement
rather than on complic	ance or noncompliance.

-Consumer/advocate

- Providers who offer hope—and who sustain that hope when patients cannot.
- Providers who are familiar with, and attend to, the needs, data, and evidence for special populations, including children (at various developmental stages); gay, lesbian, bisexual, and transgender individuals; women and men; racial and ethnic minorities; immigrants and refugees; persons in the criminal justice system; trauma victims and survivors; and older persons.
 - ... We know that children, older adults, and people in rural areas are very much underserved in terms of their mental health needs.

-Family member, primary care provider, educator

 Primary care providers who monitor the physical side effects of medications.

An "electric" feeling I described, which the primary care doctor thought originally was part of my psychosis, turned out to be a reaction to a medication.

—Consumer/advocate

- · Providers who incorporate wellness into care.
- Consumer awareness of how to navigate the health care system. Local resource guides can help increase access to information about services.
- Consumers who engage in self-advocacy and have knowledge
 of their own needs and their State-specific consumer rights.
 Self-advocacy incorporates, for example, advance directives;
 peer advocacy and the use of durable powers of attorney; and
 adequately empowered, well-funded consumer ombudsmen.
- Creation and use of advance directives and proxies for health care to accommodate situations when consumers cannot selfadvocate.

Person-Level Factors That Hinder Recovery

Dialogue participants also identified a number of factors that hinder recovery. They considered the broad area of stigma and discrimination to be an overarching negative factor. Other factors included

- Primary care and mental health providers who lack interest, or knowledge, in working with the medical problems of persons with mental illnesses;
- Providers who do not follow through and who are bound by arbitrary time constraints;
- Providers or consumers, or both, who take an "us versus them" perspective and who experience conflict over who is "in charge" rather than developing a partnership;
- Providers who ignore or are unaware of wellness and prevention perspectives; and
- Consumers who fear medical treatment, perhaps as a consequence of trauma, and do not seek help for general medical complaints.

... We can place blame on a medical care system, which we have a hard time accessing, for doctors who don't know how to talk to us, don't trust what we say, and don't adequately report our symptoms.

-Consumer/advocate

Issues Related to Systems and Contexts

Participants identified a number of system-level factors that they know promote or hinder recovery. **System** refers to a broad range of jurisdictions—Federal, State, and local departments of mental and general health, and communities in general.

System-Level Factors That Promote Recovery

Dialogue participants identified a series of system-level factors that promote recovery at the intersection of general medical and mental health care. They recognized as an overarching theme the importance of integration and coordination of mental health and primary care services, so that everyone's multiple needs are met, individuals are tracked who are served by both systems, and no one falls through the cracks. Other system-level factors that promote recovery were discussed, primarily in the categories of service provision, community connections, advocacy, and research.

... We have provided primary care at our clinic for thirty years. We have incorporated pharmacy, dental, pediatrics, OB-GYN, and recently mental health services. We treat the family. Our patient population is uninsured, underinsured, uneducated, and unaware of rights and resources. We takea holistic approach. It takes away the stigma when no one else knows why they're coming through our doors.

-Mental health administrator

Service provision

 Flexibility in handling individuals' health needs at the point of entry to the service system, using such models as co-located general medical and mental health care, primary care providers who work in mental health settings, and mental health providers who work in primary care settings.

... Every door should be the right door to obtain treatment. The greatest system challenge is to create a health care system to meet everyone's needs, like an amoeba that shapes around

anyone who walks through the door. And we need research that creates evidence to show that not doing so has a deleterious impact on the community.

—Policymaker

- Primary and mental health providers who have acquired cultural competency skills related to mental illnesses (e.g., understanding the relationship of consumers' cultures to their attitudes toward mental and general health care; the impacts of personal trauma and historical abuses; and ethnopharmacology, which is the study of differences in response to drugs based on varied ethnicity, such as drug metabolism, dosing, and side-effects).
- Mental health service providers trained to assess consumers' primary care needs and who refer them appropriately for care.
- Primary care providers trained to assess and treat or refer persons with mental disorders.
- Incentives for providers to implement proposed and existing mandates regarding integration of general medical and mental health care.

. . . Incentives, such as proper reimbursement or continuing education units, may help to produce outcomes such as choice or good practices.

-- Consumer-operated service provider/advocate

- Consumer ombudsman programs that serve primary care settings.
- Data tracking that provides evidence to support funding for quality improvements.

... We need to find out why people are dying. Death rates of people with serious mental illness are very high. Obesity puts people at risk, but some care issues in the medical and surgical sectors are unaddressed. A pilot study of community psychiatric patients in the 1990s found many cases of oversedation with antipsychotics, discharge without adequate instructions, and no communication between physicians, between services, or with the family.

—Primary care provider, researcher

Community Connections

- Inclusion of mental health assessment and services in school health programs and establishment of school-based clinics.
- Primary care representatives who are involved in consumer and community advocacy initiatives.
- Resource guides that identify community resources for primary care and mental health, to foster referrals by providers to appropriate services.
- Communities that offer supports for consumers.
- Advocacy mechanisms to engage support for consumers from the community.

Advocacy

- Education of policymakers, health care providers, and other stakeholder groups on the need for integration of primary and mental health care and on the need to understand that health problems such as obesity, hypertension, and smoking should not be viewed as inevitable byproducts of having mental illnesses and taking psychotropic medications.
- Identification of State leadership in mental health to target for education.
- Grassroots efforts to promote integration of primary and mental health care among providers and other stakeholders.
 - ... The American Academy of Pediatrics has made mental health a priority issue and has established a mental health task force to help primary care physicians provide behavioral health services in primary care settings.
 - -Family member, primary care service provider, educator

Research

- Development and funding of a research agenda, including research on the health needs of special populations and the benefit of coordinating care between mental health and primary care providers.
- Efforts to promote translation of research into practice.
- Significant involvement of consumers in research initiatives.

... The National Institutes of Health has embraced community-based participatory action research as an evidence-based practice. When the community is involved in research, the findings are more likely to come into play later on.

-Consumer/advocate

- Community-based participatory action research (as adopted by the National Institutes of Health) that fosters relevancy of the research to the community.
- International research as a resource for perspectives and approaches to mental health care.

. . . The real, serious questions that affect our lives are not touched by researchers.

-Consumer/advocate

System-Level Factors That Hinder Recovery

Overarching systemic factors that hinder recovery include

- Lack of access to mental health care or primary care, or both;
- Higher rates of co-occurring general medical disorders in people with mental health disorders;
- Stigma and discrimination;
- Lack of a public health approach and systems that are sufficiently flexible to address all health needs;
- Lack of integrated and coordinated care between primary care and mental health providers; and
- Absence of a "no wrong door" policy that accommodates consumers wherever they seek care.

In addition, participants identified a long list of system-related factors that impede recovery, including issues related to service provision, community connections, research, public policy, and consumer issues, plus a number of other concerns.

... Many mental health consumers never see a mental health professional and are more likely to receive assistance for mental health needs in the primary care system. People with serious mental illness experience disparities in terms of the prevalence of such general health problems as heart disease and diabetes. More of them die sooner from these conditions, and some medications may predispose them to chronic conditions. People of color are predisposed to chronic disease. We need to be aware of this double or triple whammy.

-Mental health provider, advocate, educator

... Different settings of care put consumers at risk. The question of who is "in charge" of a consumer's care after discharge from the hospital remains unclear. A primary care provider who is watching blood levels needs to work with the prescribing psychiatrist.

-Consumer/advocate

. . . Lack of access sometimes drives people to go to jail deliberately to get effective and coordinated health care. Then the Justice Department pays for health care, not Medicaid or Medicare.

—Consumer/advocate, service provider

Service provision

- Persons with mental health problems who lack access to specialty providers.
- Lack of electronic medical records and appropriate confidentiality and other safeguards to help track persons between care systems.
- Within managed care, insufficient time for providers to deal with complex problems, particularly those of persons who do not always communicate clearly.
- Medical education that does not teach the practical skills necessary to cross the mental health and primary care divide.

Family medicine offers a limited training perspective on how to be a family care-oriented mental health provider.

—Primary care provider

- Lack of awareness or focus, or both, on the specific needs of men and of women, and the needs of persons with cooccurring mental health and general medical disorders.
- Lack of awareness or focus, or both, on basic nutritional knowledge and other health promotion issues.

... Understanding wellness and preventive care does not happen in the public mental health system. When I do recovery training sessions for provider staff and I bring up the concept of helping people with smoking cessation and active lifestyles, the staff usually tell me they have too many other issues to worry about or it would be too stressful—as if obesity and heart disease among their clients were not stressful.

—Consumer/advocate, service provider

- Lack of cultural competence among providers. Relatively few providers recognize or understand the legacy of historical trauma or the unique needs and attitudes of minorities toward mental health and mental illness.
- Lack of trauma-informed services, or training in how to provide the services, offered by most mental health and primary care providers. Physical examinations can result in retraumatization of consumers who have experienced trauma (including seclusion and restraint).

... Some kinds of trauma events affect our ability to receive certain kinds of primary care, such as dental or gynecological. Practitioners need to be educated about the realities of trauma and how to deal with it when it turns up in their patient population.

-Consumer/advocate

- Reduction in inpatient hospital beds, which puts the availability of acute psychiatric care at risk.
- Lack of a partnership relationship between consumers and their mental health service providers.

. . . The mental health system is the only system where coercion is part of the culture.

-State policymaker

... What turned things around for me was a psychiatrist whose greatest interest was asking questions and listening and researching some more, and asking and listening. The crux is the relationship and the understanding that you both have valuable information that can be shared back and forth.

-Consumer/advocate

- Inadequate patient safety concerns at the interface of primary care and mental health care.
- Primary care physicians, including pediatricians, and psychiatrists accorded lower status by practitioners in other specialties, a form of stigma and discrimination.

. . . Often family care physicians, psychiatrists, and pediatricians are the lowest paid in terms of "pecking order." Incentives are lacking, so the pool of providers burns out and turns over.

-Primary care provider

Community Connections

- Schools that do not recognize or refer for treatment students with unmet primary care or mental health needs, or both.
 - ... Schools can play an important role in recognition, advocacy, and treatment of mental disorders.
 - -Family member, primary care provider, educator
- Inadequate connections between schools and parents.
- Absence of appropriate advocates for students with special health (including mental health) needs.
- · Lack of funding for school-based clinics.
- Lack of partnerships, informed by consumer voices, at the policy level among hospitals, the community mental health system, academic centers, and governments.
- Lack of support to identify and eliminate disparities among racial, ethnic, and other minorities, including the GLBT community.

... Many consumers have turned to the faith community before coming to mental health specialty centers for care. It makes sense to develop relationships with the faith community. Providers can learn from faith leaders about their conceptions of mental illnesses or mental health and offer them support to help their congregants.

-Mental health provider, advocate, educator

Research

- Lack of research on the medical care of mental health consumers in terms of quality of service delivery and safety.
- Insufficient research on ethno-pharmacology, which is the study of differences in response to medicines based on one's ethnicity.
- Limited role of consumers in research and in training sessions for consumer and provider partnership grants.
- Children omitted from the research agenda.
- Consumers distrustful of, and not engaged in, research.

Research is needed on issues that members of minorities have, including gay, lesbian, bisexual, and transgender (GLBT) people. They have higher rates of smoking, women have higher rates of diabetes, and men have higher rates of sexually transmitted

diseases and AIDS. And we don't have a comprehensive picture of the mental health needs of the gay community.

-Consumer/advocate

Public Policy

- Inadequate reimbursement for care given by mental health service providers.
- Inequitable, inadequate reimbursement for coordination of care between mental health and primary care systems.

... Therapists don't talk with primary care doctors. I have not figured out where I need to go and where I need to look to further my recovery. It's a hard system to figure out.

—Consumer, policymaker

. . . Coordination of care is not currently reimbursed, despite the Institute of Medicine's identification of this barrier.

—Primary care provider, researcher

- Billing and coding rules that do not provide for mental health care in primary care services.
- Discriminatory laws and regulations that impede equal insurance coverage over the lifespan for mental and general medical disorders, that establish barriers to treating cooccurring mental health and substance abuse problems, and that prohibit qualification of persons with mental illnesses for organ transplants.

... Over the years, the mental health and substance abuse communities have been at odds. When people come in with both needs, no one takes responsibility for both issues.

-Mental health provider, advocate, educator

- Gaps in Medicaid coverage and coordination and lack of awareness about mental health services covered by Medicaid.
- Uneven access to care due to geography and other demographic factors.
- Insufficient attention to co-occurring mental health and primary care needs in solicitations for applications for grants.

Consumer Issues

- Definitions impact policy; some consumers assert that the terms "self-determination" and "psychiatric disability" appear incompatible.
- Peer-to-peer stigma regarding who is a consumer.

Recommendations for Action

Plato said, "The greatest mistake in the treatment of diseases is that there are physicians for the body and physicians for the soul, although the two cannot be separated." This was a call for connection, for integrating mental health into overall health and well-being.

—Former U.S. Surgeon General David Satcher (2004)

Dialogue participants proposed a series of recommendations for action by relevant stakeholders, such as Federal and State agencies, policymakers, providers of mental health and primary care, advocates and educators. Major categories include communication and engagement on the integration of medical and mental health care, stakeholder education, stakeholder accountability, research considerations, and financing issues.

1. Communication and Engagement of Mental Health and Primary Care Providers in Integrating Care

Overarching principles include development of training modules on inclusion and access and consumer involvement in working with providers.

Policy

- 1.1. SAMHSA should collaborate with the Health Resources and Services Administration (HRSA) and the Centers for Medicare and Medicaid Services (CMS) to devise financing policies to foster integrated care.
- 1.2. Develop materials to clarify, for all health care providers, the confidentiality provisions associated with the Health Insurance Portability and Accountability Act (HIPAA).
- 1.3. Create standardized protocols for the exchange of information between primary care and behavioral health care providers, including school-based providers.
- 1.4. Review and identify a point person in each State to promote recommendations in the report by the National Association of State Mental Health Program Directors (NASMHPD) on integrating behavioral health and primary care services (see Parks & Pollack, 2005).

- 1.5. Incorporate integration efforts with Welfare to Work and Ticket to Work programs.
- 1.6. Concentrate efforts on issues relevant to underserved populations.

Program development

- 1.7. Develop a Wellness Recovery Action Plan (WRAP) program for primary care, self-care, and self-management support.
- 1.8. Promote placement of nurse practitioners in community mental health settings for routine primary care.
- 1.9. Develop quality improvement programs for providers, including incentives to improve care.
- 1.10. Develop a quick screening tool for primary care providers to determine patients' preferences for level of their participation in determining care.
- 1.11. Develop a role for peer support specialists in primary care.

Consumer-related activities

- 1.12. Develop a national consumer association.
- 1.13. Provide communications training for consumers to work with providers.
- 1.14. Conduct similar dialogue meetings among stakeholders at the local and State levels to highlight consumer involvement in integrated care.
- 1.15. Offer incentives for training of providers by consumers.
- 1.16. Develop a Web site to promote primary care and behavioral health integration.
- 1.17. Train emergency room staff in behavioral health issues.
- 1.18. Develop an anthology of stories of what works, from both consumers and providers, to help identify good models of integration and coordination of primary and mental health care.

1.19. Develop a speakers bureau on the integration of mental health and primary care to address stigma issues related to access of quality care and mental illness.

2. Stakeholder Education

Stakeholders include policymakers, primary care providers, mental health care providers, consumers, families, community representatives, and others.

Provider issues

- 2.1. Create opportunities to meet provider needs for training (e.g., on consumer involvement in care, cultural competence, and motivational interviewing).
- 2.2. Conduct an initiative to improve care options for members of minority groups (e.g., the American Psychiatric Association's minority outreach initiative targets primary care providers and faith-based organizations).
- 2.3. Collaborate with Morehouse School of Medicine's National Primary Care Center on integrated care.
- 2.4. Establish a 1-year certification program in mental health for primary care providers.
- 2.5. Educate dentists about working with clients who have mental health problems.
- 2.6. Create incentives for information acquisition regarding the integration and coordination of primary and behavioral health care.
- 2.7. Train front-office staff of primary care providers to interact with persons with mental health problems.
- 2.8. Offer technology or Internet training on the benefits and implementation of integrated mental health and primary care services.
- 2.9. Replicate this dialogue model within mental health and primary care settings.
- 2.10. Train mental health providers in the importance of addressing general health needs and of coordinating care between general medical and mental health providers.

Consumer involvement

- 2.11. Educate providers and staff to realize that consumer involvement has positive outcomes.
- 2.12. Educate stakeholders on the effectiveness of consumer-operated services.
- 2.13. Educate consumers about how to improve interactions with primary care providers.
- 2.14. Educate first responders (e.g., police, fire, and ambulance) on appropriate responses in situations that involve mental health consumers.
- 2.15. Educate consumers about their rights.
- 2.16. Educate consumers to advocate for themselves and peers.

Resource development

- 2.17. With the Department of Veterans Affairs and other relevant organizations, develop curricula on trauma and its consequences for health.
- 2.18. Target education of, and partnerships between, employers and purchasers of health care regarding innovative programs to integrate primary and mental health care in the workplace.
- 2.19. Survey primary care provider guilds' approach to training and publish and disseminate a report on successful integration models.
- 2.20. Develop resources to educate stakeholders on cost savings related to prevention programs and increased access to care.
- 2.21. Develop materials and integrate recovery into curricula for training providers.

3. Stakeholder Accountability

We need accountability for research, reimbursement, and engagement. We need mechanisms to hold everyone, including funders, consumers, and providers, accountable.

—Consumer/advocate, service provider

- 3.1. Plan for and track quality improvement, including development of a consumer evaluation form and a single set of standards and measures for providers. Planning and implementation must be collaborative and must incorporate both significant input from consumers and involvement of accreditation organizations.
- 3.2. Publish report cards for satisfaction and dissatisfaction at all levels and for all stakeholders. Consumers should interview consumers, to reduce threat of loss of care by providers, and questionnaires should be developed that are appropriate for consumers who cannot read.
- 3.3. Hold managed care organizations accountable, and survey providers on their experiences.
- 3.4. Focus on compliance with the Americans with Disabilities Act in terms of access to care.
- 3.5. Develop tools for training and tracking outcomes, and provide incentives for providers to track outcomes.

4. Research

A top priority is the translation, dissemination, and implementation of what we know to work.

- -Primary care provider, educator, researcher
- 4.1. Focus research on recovery-oriented practices to add to the evidence base of programs that work.
- 4.2. Create a guide that describes the latest research in mental health and primary care.
- 4.3. Review the literature on international research.
- 4.4. Support community-based, participatory action research; use consumer-run research as part of larger grants; require consumer direction of research and accountability to the community.
- 4.5. Provide funding to evaluate consumer-operated programs (e.g., small incentive grants).
- 4.6. Provide funding to expand the evidence base for best models of coordination between primary care and specialty mental health providers.

- 4.7. Provide technical assistance to consumer researchers.
- 4.8. Conduct research on the effectiveness of "alternative" therapies, such as physical exercise or yoga.
- 4.9. Conduct research on pharmaceuticals' side effects related to such concerns as sleep, nutrition, and a holistic approach.

5. Finance

Creating better access to health care lowers costs. After decreasing barriers to outpatient mental health services in 1992, North Carolina's State Employee Health Plan experienced a 70 percent reduction in mental health hospital days and a steady reduction in average per member/per month costs for the next six years.

—Family member, primary care service provider, educator

Funding

- 5.1. Ensure that systems have the resources to provide high-quality general medical and mental health care.
- 5.2. Address the high cost of medications.
- 5.3. Raise pay scales for psychiatrists.
- 5.4. Eliminate mental health carve-outs from managed care plans to reduce fragmentation (need a single point of entry).
- 5.5. Develop a report that demonstrates the costeffectiveness of increased access to mental health and primary care, pooling data from separately funded programs.
- Increase funding for pilot programs for self-directed care.

Reimbursement

- 5.7. Provide reimbursement in all States for all mental health providers, including certified peer specialists and other consumer-providers, and providers of respite and home care.
- 5.8. Provide reimbursement on a continuum of care provided by community mental health centers.
- 5.9. Provide reimbursement for collaboration between professionals, that is, reimbursement for physician-

- to-physician, mental health professional-to-physician, and physician-to-mental health professional consultation.
- 5.10. Increase Medicaid buy-in programs and disseminate information nationwide.
- 5.11. Eliminate the lifetime cap on reimbursement for Medicare inpatient care.
- 5.12. Conduct a financial review and reform such procedures as billing, coding, and reimbursement to ensure delivery of appropriate mental health services in primary care settings.

Community collaboration

- 5.13. Develop partnerships between general medical and mental health community-based service organizations.
- 5.14. Collaborate with unions on workplace initiatives.
- 5.15. Create a toolkit to help stakeholders educate legislators and other policymakers.

Incentives

- 5.16. Offer incentives for training to primary care providers in how to care for people with mental illnesses
- 5.17. Establish work incentives for consumers, providing such supports as personal care assistants.
- 5.18. Establish incentives that promote self-directed care, consumer control and choice of services, and a wider variety of services.

6. Planned Actions in the Community

To close the dialogue meeting, participants identified a number of activities they planned to undertake in their communities. They recognized that this effort requires maximizing creative thinking about where the best points

- of intersection and intervention are to implement systems transformation. Planned community actions included
- Increased interaction with the broader disability community, including mental health, developmental disability, and other systems with similar issues;
- Increased engagement at the State level with CMS to broaden the availability of Medicaid coverage;
- Replication of dialogues on the local and State levels among mental health consumers and representatives of the mental health and primary care sectors as a consciousness-raising effort; and
- Organization of community events where primary care providers and mental health providers can meet to establish connections.
 - ... Primary care must see mental health as part of its charge and responsibility, and vice versa. The ultimate goal is for primary care and mental health care to work together. Developing a coordinated plan is the context for all work.

—State policymaker

Innovative Mental Health Treatments and Services

The New Freedom Commission's Subcommittee on Mental Health Interface with General Medicine (2003b) observed that although highly effective treatments are available for mental disorders, a number of patient, provider, and system-level barriers impede the effective delivery of these treatments. The subcommittee identified a number of ingredients necessary to improve care for common mental disorders at the interface of general medicine and mental health. Many of these ingredients are congruent with those identified by participants in the dialogue:

- 1. Educated consumers, primary care providers, and mental health providers.
- 2. Efficient and effective methods to screen for, diagnose, and monitor common mental disorders in primary care.
- 3. Information systems that can support proactive tracking of both quality and outcomes of care by primary care and specialty mental health providers in order to prevent patients from "falling through the cracks."
- 4. Well-established performance criteria for quality of mental health care at the interface of general medicine and mental health.
- 5. Evidence-based, collaborative, and stepped care treatment protocols that match treatment intensity to clinical outcomes.
- 6. Trained mental health staff (psychiatrists, psychologists, clinical social workers, or other mental health workers) who can support primary care providers with education, proactive followup, case management, psychotherapy, and consultation for patients who do not respond to firstline treatments in primary care.
- 7. Effective mechanisms to refer patients who do not improve with treatment in primary care to specialty mental health care and to coordinate treatments between primary care and specialty mental health care.
- 8. Financing mechanisms for evidence-based models of care for common mental disorders in primary care. These mechanisms include payment for case management for common mental disorders in primary care according to evidence-based protocols, consultation to primary care providers and supervision of mental health case managers by qualified mental health specialists, psychotherapy at copayment rates equal to those for the treatment of general medical disorders, and prescription medications for common mental disorders.

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Federal and Other Resources

Center for Mental Health Services Substance Abuse and Mental Health Services Administration U.S. Department of Health and Human Services

The Center for Mental Health Services (CMHS) leads the national system that delivers mental health services in order to provide the treatment and support services needed by adults with mental disorders and children with serious emotional problems. SAMHSA's three centers, CMHS, the Center for Substance Abuse Prevention, and the Center for Substance Abuse Treatment, along with other Federal agencies, have inaugurated a new collaboration to span the silos of general medical and mental health care.

Address: 1 Choke Cherry Road, Rockville, MD 20857

Web site: www.mentalhealth.samhsa.gov

Enews Alert: www.mentalhealth.samhsa.gov/onsumersurvivor

(see signup at bottom of screen)

Funding opportunities: www.samhsa.gov

(click on Hot Topics, "New Grant Funding Opportunities")

Resource Center to Address Discrimination and Stigma:

www.adscenter.org

Elimination of Barriers Initiative:

www.allmentalhealth.samhsa.gov;

in Spanish:

www.nuestrasalud.samhsa.gov

Centers for Disease Control and Prevention: Coordinated School Health Program

The Centers for Disease Control and Prevention's coordinated school health program model consists of eight interactive components. These components are health education, physical education, health services, nutrition services, counseling and psychological services, healthy school environment, health promotion for staff, and family/community involvement.

Web site: www.cdc.gov/HealthyYouth/CSHP/index.htm

Health Resources and Services Administration, Bureau of Primary Health Care

The Health Resources and Services Administration (HRSA) ensures that underserved and vulnerable people get the health care they need through a nationwide network of community and migrant health centers and health care for the homeless programs. Materials are available on primary health care, access, insurance, and other topics from the HRSA Information Center. HRSA's Primary Care Integration Initiative aims to eliminate disparities of underserved individuals and families with primary mental health and substance abuse disorders. By 2006, HRSA expects to expand dramatically the number of people nationwide served by new and existing community health centers that provide mental health and substance abuse treatment in addition to primary medical care (Parks & Pollack, 2005).

Web site: www.hrsa.gov

HRSA Information Center: www.ask.hrsa.gov/Primary.cfm

National Institute of Mental Health

The National Institute of Mental Health's (NIMH's) Primary Care Research Program conducts studies on the delivery and effectiveness of mental health services within the general health care sector; recognition, diagnosis, management, and treatment of mental and emotional problems by primary care providers; coordination of general medical care with, and referrals to, mental health specialists; provision of psychiatric emergency services, consultation and liaison psychiatry, and other psychiatry, psychology, and social work services within the general medical care sector; and studies that improve understanding of how best to improve care for people with mental disorders and cooccurring general medical conditions.

NIMH Primary Care Research Program (82-SEPC)

Contact: Carmen Moten, Ph.D., Chief,

Primary Care Research Program

Address: 6001 Executive Boulevard, Room 7146/MSC 9631,

Rockville, MD 20852

Telephone: 301-443-3725 E-mail: cmoten@mail.nih.gov

American Academy of Family Physicians

The American Academy of Family Physicians (AAFP) has compiled a policy statement on mental health and a position paper on mental health care services by family physicians.

Address: P.O. Box 11210, Shawnee Mission, KS 66207-1210

Telephone: 1-800-274-2237; 913-906-6000

Web site: www.aafp.org

Policy statement on mental health: www.aafp.org/x6925.xml "Mental Health Care Services by Family Physicians (Position

Paper)": www.aafp.org/x6928.xml

American Academy of Pediatrics

The American Academy of Pediatrics (AAP) offers information on children's behavioral health and professional education and resources. The group has established a task force to help primary care physicians provide behavioral health services in primary care settings.

Address: 141 Northwest Point Boulevard,

Elk Grove Village, IL 60007-1098

Web site: www.aap.org

American Association of Community Psychiatrists

The American Association of Community Psychiatrists has recommended that mental health and substance abuse treatment providers at the local level incorporate a systematic program to coordinate or integrate with primary care providers and organizations in their communities, with the goal to improve bidirectional communication, share essential information, and adopt appropriate confidentiality and consent protocols (Parks & Pollack, 2005, 5).

Address: University of Pittsburgh, 3811 O'Hara Street,

Pittsburgh, PA 15213

Web site: www.comm.psych.pitt.edu

"Position Paper on Interface and Integration with Primary Care Providers" (October 2002): www.comm.psych.pitt.edu/

finds/primarycare.htm

American Psychiatric Association

Integration of mental and general health is a priority of the American Psychiatric Association (APA), which is developing an initiative to address the issues. An ongoing APA program is Bridging the Gaps between Dental Health and Mental Health.

Address: 1000 Wilson Boulevard, Arlington, VA 22209

Telephone: 1-888-357-7924 Web site: www.psych.org

American Public Health Association

The American Public Health Association (APHA) promotes the scientific and professional foundation of public health practice and policy, advocates the conditions for a healthy global society, emphasizes prevention, and enhances the ability of members to promote and protect environmental and community health.

Address: 800 I Street, N.W., Washington, DC 20001

Telephone: 202-777-APHA (202-777-2742)

Web site: www.apha.org

Community Voices: HealthCare for the Underserved

Managed by the National Center for Primary Care at the Morehouse School of Medicine, Community Voices sites are making a significant contribution to understanding the health care challenges facing communities, advancing recommendations for change, and implementing solutions. Community Voices is designed to strengthen community support services and to help ensure the survival of safety net providers. Communities are piloting various approaches and strategies and bridging health care delivery to underserved populations with new policy solutions.

Web site: www.communityvoices.org

The Northern Manhattan Community Voices Collaborative's "Mental Health: The Neglected Epidemic: Convening and Promoting a Dialogue Among Consumers, Providers and Policy Makers": www.communityvoices.org/non_publication_pdfs/NM-MentalHealthPaper.pdf

Health Guide USA: Primary Care Association

This Web site offers users access to a wide variety of online health care-related resources, including primary care associations.

Web site: http://healthguideusa.org

National Association of Community Health Centers

The National Association of Community Health Center's (NACHC's) Web site reflects its commitment to help those involved with America's community, migrant, and homeless health centers, including Federal and State policymakers, primary care associations, health centers, clinicians, and patients.

Address: 7200 Wisconsin Avenue, Suite 210, Bethesda, MD 20814

Telephone: 301-347-0400 Web site: www.nachc.com

National Association of State Mental Health Program Directors

A nonprofit organization dedicated to serving the needs of the nation's public mental health system through policy development, information dissemination, and technical assistance, the National Association of State Mental Health Program Directors (NASHMPD) published in 2005 a technical report on the integration of behavioral health and primary care services.

Address: 66 Canal Center Plaza, Suite 302,

Alexandria VA 22314

Telephone: 703-739-9333 Web site: www.nasmhpd.org

"Integrating Behavioral Health and Primary Care Services: Opportunities and Challenges for State Mental Health Authorities": www.nasmhpd.org/general_files/publications/med_directors_pubs/Final%20Technical%20Report%20on%20 Primary%20Care%20-%20Behavioral%20Health%20Integration. final.pdf

National Council for Community Behavioral Healthcare

The National Council for Community Behavioral Healthcare (NCCBH) is a trade association that represents the providers of mental health, substance abuse, and developmental disability

services. In May 2003, the council published a background paper on behavioral health and primary care integration.

Address: 12300 Twinbrook Parkway, Suite 320, Rockville, MD 20852

Telephone: 301-984-6200; fax: 301-881-7159

Web site: www.nccbh.org

"Background Paper: Behavioral Health/Primary Care Integration Models, Competencies, and Infrastructure": www.nccbh.org/HTML/LEARN/PCI/PrimaryCareDiscPaper.pdf

National Mental Health Association

The National Mental Health Association's (NMHA's) Primary Care Initiative reaches out to providers to improve the manner in which depression and anxiety are detected and treated in primary care settings, particularly to make certain that individuals who have been encouraged to seek treatment for depression and anxiety disorders can be assured that their provider is aware of the prevalence, symptoms, and treatment of these illnesses. NMHA has developed educational programs and materials for practitioners and patients, as well as fact sheets about depression and anxiety disorders in primary care settings, and distributes free educational materials, brochures, and screening tools; provides access to support groups and referral networks; and provides technical assistance and consultation as needed to primary care practitioners and health care partners interested in participating in this initiative.

Address: 2001 North Beauregard Street, 12th Floor,

Alexandria, VA 22311

Telephone: 1-800-969-NMHA (1-800-969-6642)

Web site: www.nmha.org

ParentsMedGuide.org

The American Psychiatric Association and the American Academy of Child and Adolescent Psychiatry have posted guides on this Web site to help patients, families, and physicians make informed decisions about obtaining and administering the most appropriate care for a child with depression. The guides have been endorsed by many national medical, family, and patient advocacy organizations.

Web site: www.parentsmedguide.org

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